

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 23, 1998

American Indian, Lower Education

Tulsa, Oklahoma

Moderator: Gale Marshall

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- AIDS
- Chickenpox
- Cancer
- Crippling
- Hepatitis

II. Immunization

A. Reasons to get vaccinated

- To keep children safe/healthy
- To keep epidemics down
- To keep the spread of disease down
- Because it works
- Lower risk of getting disease

A. Reasons not to get vaccinated

- Risk of getting disease from immunization
- Fear of allergic reactions
- Lack of money
- Lack of knowledge
- Procrastination
- Neglect

B. Ways parents are reminded of vaccine schedule

- Record card at birth of baby
- Call the doctor
- Doctor sends notice
- Hospital/clinic notices
- Schools and preschool notices

C. Methods of easier tracking

They keep it pretty simple. ----- has a campaign going [called] 'due by 2.' They have commercials and everything so you know you must have them done by two.

Reminders are great. They're wonderful.

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the type of information typically in a registry

- Respondents generally agreed that a registry was a positive. They particularly liked having easy access if records were lost, or the family relocated or changed doctors. Respondents were concerned about confidentiality and privacy, the accuracy of information in the registry, and the possibility of computer fraud.

I like the idea.

My child's not always done in the same place. The pediatrician has done some, the health clinic has done some. You're going to be running back and forth.

My wife takes care of all that stuff. She has it all in a file, and I just don't mess with it. But if our house burned down, if it was in a registry, we could always get copies of it and it would be a lot easier than the way it is today.

II. Content of the registry

A. Initial reaction to the type of information typically in a registry

- Respondents were most comfortable with the company that made the vaccine, the lot number, and the date it was administered. The suggestion was made that the father's name/custodial parent's name, as well as the doctor's name be included. Authorization for access was also suggested.

I think it's good. I don't think it's anything that I wouldn't want someone to know. I wouldn't mind my name being on there and my maiden name. Seems okay to me.

B. Reactions to including home address and telephone number

- Initially there were concerns about address and telephone number but as the discussion continued were more agreeable to including the address.
- Respondents agreed that the address would be necessary to assist in contacting families if something was wrong with a batch of vaccine. They were less comfortable with including the telephone number. [NOTE: In this group two women voiced a great

level of concern throughout the discussion about the possibility that non-custodial parents could use the registry to obtain information on children.]

C. Reactions to including parent or child Social Security number

- Although reactions were mixed, it was generally felt that this information is available anyway. It was suggested that the SSN be optional so someone uncomfortable with including that information would still participate in the registry.

Everybody's information, it's so readily available. You can go down to the courthouse and they'll tell you how to pull it out. To me it's just another thing to make life easier for parents.

D. Reactions to including healthcare member's enrollment (WIC, Medicaid numbers, tribal enrollment numbers)

- Respondents were more comfortable with WIC and Medicaid versus tribal enrollment numbers. Issues of security and privacy were noted.

Why would they need that? You're getting into there already, let's make this a little bigger, let's squeeze this in. Well what about this too? Okay, here's my life.

III. Access

A. Who should have access

- Custodial Parents
- Physicians
- Healthcare Providers
- Emergency contact person
- Law enforcement
- School nurse/ Administrators
- Researchers, if access is limited to certain information

B. Who should not have access

- The Internet
- Some researchers
- Health Insurers
- 'people in the street'

C. Reactions to the idea of linking registry by computer to other health information

- Reactions were mixed. Some respondents said linking systems would make obtaining information more convenient, but others were concerned that if the systems were linked people could obtain medical information they would rather keep private.

IV. Consent and Inclusion

A. Reactions to “opting out” option

- Participants responses were neutral to positive.

Because if you don't want yours in the registry then you're going to take time to sit down and fill out the paperwork. If it doesn't matter to you then you'll kind of blow it off, one less thing you have to do.

B. Reactions to “consent” option

- Participants assumed that information would be sent by mail. They were concerned that if information came by mail it would be mistaken for junk mail and thrown out.
- The respondents were in general agreement that this option would be a disadvantage to researchers and healthcare providers because people who didn't care enough to sign consent might not have their children immunized.

It's going to be the last thing on my mind. When you have a newborn baby I'm busy.

You're going to lose the parents that don't care. The kids, the parents that don't care, they're not going to do the vaccinations. You're going to lose them. You have no record of them.

C. Reactions to “automatic” option

- Respondents noted the values of this option but some were concerned about not having a choice or the ability to opt out.

I'd like to have a choice. I'd like to be able to choose to opt in or opt out. Like I'd rather have a choice. I'd feel more comfortable having a choice.

But you ought to have an option to opt out. For safety reasons, you ought to have that. An American ought to have that right.

I think it would be okay. We don't really have control over a lot of things anyway. Everybody's in there, cause maybe some lazy person might think well I don't want to be tracked. They might send that card to opt out, do you know what I mean? That's kind of defeating the purpose that way so I think everybody should be in it and that's that.

SECTION 3: WRAP UP AND CLOSING

I. Most important benefits of registries

- Easy access
- Immunizations on schedule
- Research
- Keeping disease control down
- Reminder notices
- Having information about vaccine lot numbers

II. Greatest concerns/biggest risks

- Potential access by inappropriate people or agencies
- Custodial issues
- When probed about law enforcement and the government having too much information, respondents joked that these agencies already have access to information anyway.
- In response to the possibility of being denied insurance, a few respondents noted that such a possibility might motivate people to have their child vaccinated
- Respondents showed little concern about being denied entry into school. One respondent said children are already being denied entry into school if they do not have all their vaccines

III. Influence of healthcare provider in decision to participate in registry

Participants responded favorably regarding their doctors opinion.

IV. Suggestions/comments to people who are responsible for how system works

I think it's great I really do. Think of something to make our lives easier. I think it's really cool. It does, it would make our lives a lot easier. Like if you're moving, traveling and you lose that, you can always get it back.

Let's keep it for healthcare.

